

# **What are the possible futures impacts of Patient Opinion Leaders on healthcare and healthcare stakeholders ?**

Bachelor Project submitted for the obtention of the Bachelor of Science HES in  
Business Administration with a major in International Management

by

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International Business Management



## Declaration

This Bachelor Project is submitted as part final examination requirements of the Geneva School of Business Administration's for obtaining the Bachelor of Science HES-SO in Business Administration, with major in International Management.

The student accepts the terms of the confidentiality agreement if one has been signed. The use of any conclusions or recommendations made in the Bachelor Project, with no prejudice to their value, engages neither the responsibility of the author, nor the adviser to the Bachelor Project, nor the jury members nor the HEG.

"I attest that I have personally accomplished this work without using any sources other than those cited in the bibliography. Furthermore, I have sent the final version of this document for analysis by the plagiarism detection software URKUND using the address supplied by my adviser".

Geneva, May 29<sup>th</sup> 2015

Meryl DIX

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Last but certainly not least, I sincerely would like to say thank my parents and brother for their unconditional support.



## Executive Summary

The aim of this project is to find out what are the potential future impacts of Patient Opinion Leaders (POLS) on healthcare and healthcare stakeholders. Because there exists many different definitions for POLS, the following definition will be consistently used for the sake of this project:

A Patient Opinion Leader is a patient that suffers (or has suffered) from (a) chronic disease(s), either mental or physical, and that shares his/her knowledge about his/her condition and treatment on the Internet through blogs, videos, social media or community websites.

In order to conduct my project, I interviewed ten people with close ties to the healthcare industry. To conduct the interviews, I used the Futures Wheel method. The goal of this method is to draft a wheel that is used to identify secondary and tertiary consequences of a certain event (here: the future of POLS).

Once all of the ten interviews had been conducted and the final Futures Wheel drafted, the data from the wheels was input into the Gephi computer software by Mr. Pierre-Alexandre Fonta, Big Data – engineer, Data Scientist and assistant at the University of Applied Sciences in Geneva. Gephi is an “interactive visualization and exploration platform for all kinds of networks and complex systems, dynamic and hierarchical graphs”<sup>1</sup>. It is used to develop cartographies in order to visualize a certain event or question.

Once the final cartography was elaborated, I proceeded to discuss it with three of the ten individuals I had interviewed. Each of the three people interviewed came up with a realistic and feasible scenario for the future in regards to Patient Opinion Leaders.

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<sup>1</sup> Source: Gephi, 2015. *Gephi – makes graphs handy*. [ONLINE]. [Accessed 18 April 2015]. Available at: <http://gephi.github.io/>

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# 1. Introduction

## 1.1. Patient Opinion Leaders (POLS)

### 1.1.1. Definition

There is not one single definition of Patient Opinion Leaders (POLS) that all healthcare stakeholders agree on. There are also many different names for referring to them such as: e-Patient, patient advocate, empowered patient or patient spokesperson. For the sake of this project, when discussing POLS, the following definition will be used.

**A Patient Opinion Leader** is a patient that suffers (or has suffered) from (a) chronic disease(s), either mental or physical, and that shares his/her knowledge about his/her condition on the Internet through blogs, videos, social media or community websites.

An imperative aspect to consider when discussing POLS is the possible impact or influence that these individuals may have on other patients. However, it is important to bear in mind that not all POLS have such an influence and that is why this aspect has not been incorporated into the definition.

### 1.1.2. Types of POLS

There exist two main types of Patient Opinion Leaders today. The first has as their main goal to help and inform other patients who suffer from the same disease(s).

Each Patient Opinion Leader in this category will decide what to discuss and what to share (on the Internet or other medium). Not every individual POL of this type is willing to divulge all of the information concerning his or her disease(s) and/or treatment(s). However, these POLS generally have three main key roles.

1. Provide information about his/her condition(s) that is directly from the “patient’s view”
2. Offer information, guidance, direction, assistance in: treatments, healthcare facilities, healthcare practitioners, healthcare services, life insurance, health insurance, exercise and diet
3. Offer support and encouragement to any patient that is suffering from the same disease(s)

This category of Patient Opinion Leaders may decide to discuss his/her condition(s) without necessarily recommending a certain treatment. Another POL within this category may decide to discuss the side effects of a certain drug without offering support/encouragement to his/her readers because he/she believes that he/she is not able to do so. The three key roles mentioned above are not necessarily all fulfilled and will differ from one POL to another. Some of these POLS might be influential by offering information and guidance in regards to certain treatments while others may only offer their support and are therefore, not influential.

The second type of Patient Opinion Leader is an individual who is more active on the advocacy front and whose aim is to influence patients and different healthcare stakeholders such as policy makers, physicians, governments and insurance companies. Some POLS decide to focus more on the first aspect while others decide to pursue the advocacy part and some decide to do both.

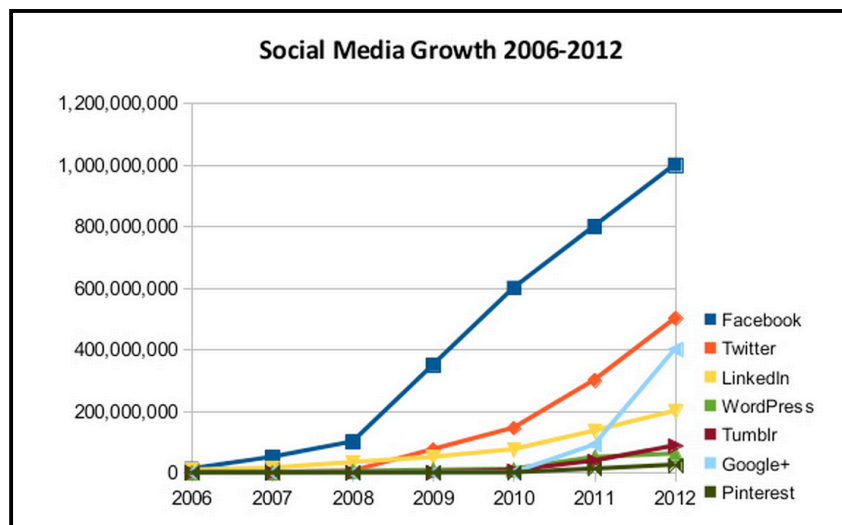
### 1.1.3. Spread

It is nearly impossible to know the number of POLS active today. There are an innumerable number of blogs, community websites, and different types of social media available for patients to discuss their condition(s).

POLS started to gain momentum due to a confluence of two main but differing aspects of today’s society. First, it is due to the Internet and the rise of social media (see figure n°1).

Exchanging information and being in contact with people who share the same disease(s) is extremely easy with social media and especially with the use of hash tags.

**Figure n°1: Social Media Users 2006 - 2012**



*Source: D Steven White (2012)*

Secondly, the Internet is an inexpensive, effective and fast way to find information and/or treatment solutions for a number of diseases ranging from the common cold to severe and rare diseases such as cancer or diabetes. Moreover, more and more people have a desire to gain more detailed knowledge about a specific condition, its treatment and the healthcare process in general. Figure n°2 shows that 66% of Internet users have searched online for “a specific disease or medical problem” and that more than half have searched for a “certain medical treatment or procedure”.

**Figure n°2: Percentage of Internet users who search online for medical questions**

% of internet users who have looked online for information about...	
66%	a specific disease or medical problem
55%	certain medical treatment or procedure
52%	exercise or fitness
47%	doctors or other health professionals
45%	prescription or over-the-counter drugs
38%	hospitals or other medical facilities
37%	health insurance, including private insurance, Medicare or Medicaid
35%	alternative treatments or medicines
33%	how to lose weight or how to control your weight
28%	depression, anxiety, stress or mental health issues
26%	any other health issue
20%	experimental treatments or medicines
12%	how to stay healthy on a trip overseas
83% of internet users, or 61% of adults, have looked online for information about at least one of these topics	

*Source: PewInternet (2012)*

It is because of these two different aspects that POLS have become more widespread on the distinctive outlets mentioned above. At times, these POLS can have many thousands of followers.



## 1.2. The research problem

The Internet has changed the way we search for information, how fast we have access to it and our general knowledge. Finding information on the World Wide Web is easy and has become second nature. We are now so used to having access to all types of information that we have effectively become more curious about the world around us and healthcare is no exception (as seen in figure n°2).

With the Internet, we have been introduced to Social Media in many different forms: Blogs, Facebook, Twitter, Instagram, Google+, Pinterest, etc., are all tools used on a daily basis and it seems that, again, healthcare has not escaped this trend. Indeed, healthcare is very present on Social Media websites as pharmaceutical companies, doctors, patients and healthcare facilities all use the sites and apps mentioned above.

More and more people search for healthcare information on the Internet (as seen in figure n°2) and according to PharmaGuy (“a constructive critic/blogger of the pharmaceutical industry”<sup>2</sup>) “online patients are looking for conversations with real people”<sup>3</sup>. Patients want to hear about and from other patients with the same disease(s) that are going through the same ordeal. This is where Patient Opinion Leaders come in to play. Using the Internet as their medium to communicate, these individuals share their experience, knowledge and advice on all of the Social Media platforms mentioned above.

Consequently, different questions come up. What are plausible scenarios for the future of Patient Opinion Leaders? Is there a method that would allow us to come up with these scenarios and are these POLS here to stay?

To answer these questions, I have interviewed ten individuals who all have a close ties to the healthcare system. They were able to clarify the subject for me, help me answer these questions and help me come up with conceivable scenarios for the future.

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<sup>2</sup> Source: Pharma Marketing Blog, 2015. *Pharma Marketing Blog*. [ONLINE]. [Accessed 27 May 2015]. Available at: <http://pharmamkting.blogspot.ch/>

<sup>3</sup> Source: PharmaGuy. 2010. Some Social Media POLS want to be paid Pharma Professionals. *Pharma Marketing Blog*. [ONLINE]. October 18 2010 [Accessed 27 May 2015]. Available at: <http://pharmamkting.blogspot.ch/2010/10/some-social-media-patient-opinion.html>

### 1.3. Cartography

The first trace of mapping or cartography can be found as early 25'000 BP<sup>4</sup>. It was first used, in the form of a drawing made with parchment and brushes, to map out land. Because of the material used and the fact that it was made by hand, distribution was difficult, scarce and the cartographies could vary in quality and representation. Cartography later evolved into mapping the whole globe and then to extensive thematic cartography.

The chosen definition for cartography for this project is the following:

**Cartography** is a discipline that deals with the total process of mapping. It begins with the gathering of data and conception of the map, continues with the production and the dispersal of the data and ends with the study of the actual map.

The subject of cartography is a very intricate one as it is an ever-changing field mostly due to the advances in technology that have happened in the last decades. It requires a mixture of knowledge in multiple fields such as data planning, technology, logic, science and can even require being artistic. Two main aspects define cartography nowadays. The first is that maps are an imperative feature in our day-to-day lives and have played a significant part in our changing civilization. Secondly, cartography can be used to determine possible future scenarios for a specific question as it has been done for this project.

### 1.4. Gephi software

The Gephi software is the cartography software that was used to input the data gathered from the interviews. The output from this software was the final cartography as seen in appendix n°7. The software was developed by 12 students from the University of Technology of Compiègne, in Compiègne, France and first launched in 2008.

This software is used to understand and arrange data. The user is able to operate and manipulate the data in order to better visualize the final outcome by adding colors, shapes and links between data and space.

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<sup>4</sup> Before present.

## 2. Methodology

### 2.1. Futures Wheel method

#### 2.1.1. What is it?

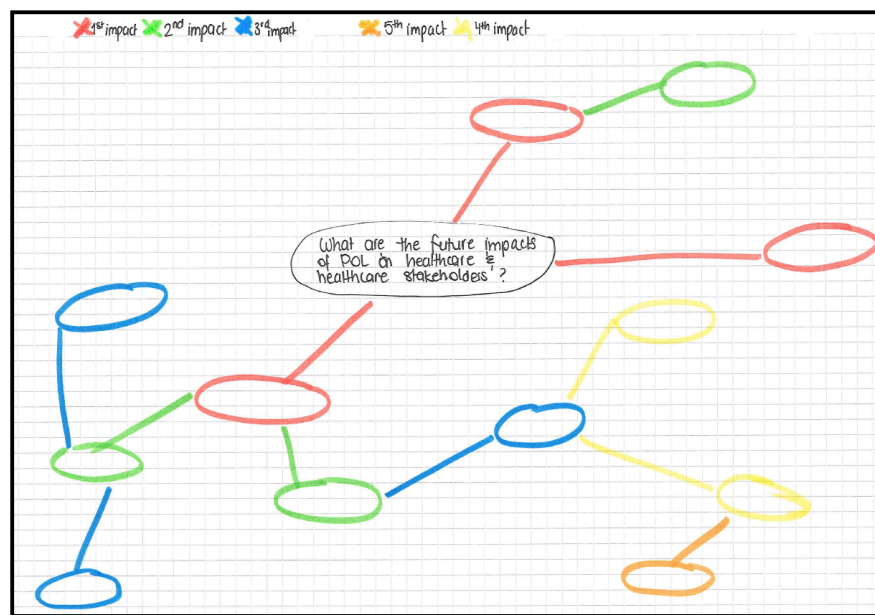
Jerome C. Glenn first invented the Futures Wheel in 1971 while still a student at the Antioch Graduate School of Education in Ohio. This method is used to draft a wheel in order to identify secondary and tertiary consequences of a certain event. As Glenn stated in his paper, it is a kind of “structured brainstorming” (1994, p.2) that helps to organize thinking and questions about the future. The author also discussed that this method can be used alone or with a group and is most commonly used to (1994, p.2):

- “Think through possible impacts of current trends or potential future events
- Organize thoughts about future events or trends
- Create forecasts within alternative scenarios
- Show complex interrelationships
- Display other futures research
- Develop multi-concepts
- Nurture a futures-conscious perspective
- aid in group brainstorming”

*Source: Jerome C. Glenn (1994)*

Creating a Futures Wheel is quite simple and only requires a pen and a blank sheet of paper. The “question” that needs to be answered is set in the middle of the sheet of paper in a “bubble” with “spokes” leaving the “primary bubble” (Glenn, 1994, p.3). Then, impacts/consequences of the question are exposed and written down at the end of each spoke. At the end of each “secondary bubble”, other spokes are drawn to show the “impacts of impacts”. This exercise is repeated until all final impacts have been written down.

**Figure n°3: Blank Futures Wheel**



Source: Meryl Dix (2015)

### 2.1.2. Limitations of the Futures Wheel method

The Futures Wheel is the direct consequence of the opinions and knowledge of the people involved. Should their opinions be false or biased, the wheel will reflect that. Also, it is possible that the person drafting the wheel will omit a certain impact/consequence (not purposefully). There is no way to “check” this and the wheel might remain incomplete. Many impacts are often unpredictable so the final wheel is not a definite and clear answer to a certain problem. On the other hand, even if one impact is written in the wheel, it does not necessarily mean that it will occur. Furthermore, this method does not take into consideration timing.

### 2.1.3. Advantages of the Futures Wheel method

This method is easy to use and requires little equipment. It does not necessitate any advanced training and the result is clear and in visual form. The Futures Wheel can be used at any time in a process and is easily adaptable to different kinds of situations. The wheel enables one to identify both “positive and negative feedback loops” (Glenn, 1994, p.7), which may be difficult to spot when using other methods. An example of a “positive and negative feedback loop” is the following: building new apartment buildings brings new inhabitants, new inhabitants need to be housed and therefore more building apartments need to be constructed.

## 2.2. Interviews

The selection of the individuals I interviewed began with the help of my project advisor, Thomas Gauthier, who worked as an engineer, clinical research director and as a research scientist at Phillips Company. Mr. Gauthier provided me with 8 names of potential interviewees that all had links to the healthcare industry. At the end of each interview, I proceeded to ask the interviewee for a list of colleagues or individuals that had knowledge in the subject that I could potentially interview. This process worked well at times but I was unable to consistently receive contact information (see table n°2 and table n°3) for different reasons. The two main reasons are the following: some interviewees said that they weren't in direct contact with a person that had knowledge of POLS. Others explained that the subject of POLS is quite new and therefore not understood/known by many (see table n°2).

After the list of the first 8 potential interviewees was exhausted, I interviewed individuals that had been referred to me by other interviewees with the exception of Dr. Catherine Herter Clavel, who is my family doctor. Two months after I started the interview process, Mr. Gauthier provided me with an extra 10 names of potential people to interview, as I was not able to receive enough referrals from other interviewees.

Two different types of people were interviewed for this project. First, there were the "professionals" who are all healthcare stakeholders such as doctors, consultants and engineers. Each of these people either works in a field that is related to healthcare or has done so in the past. Secondly, I interviewed POLS that are active on the advocacy front.

All interviewees were contacted by e-mail (see appendix n°2) with the exception of Dr. Herter Clavel. The interviews were conducted by phone with the exception of two. The one conducted with Dr. C. Herter Clavel which was done face to face and the second conducted with Mrs. Boyer Barresi that was done with a series of questions sent by e-mail (see appendix n°5). Each interview lasted between 30 to 45 minutes. I started out each interview by introducing myself and explaining why I was doing this project. Next, I asked the interviewee to introduce him/herself in order to understand what were his/her ties to the healthcare industry. Then, I proceeded with the interview by asking only one question: What are the futures impacts of Patient Opinion Leaders on healthcare and healthcare stakeholders?

The Futures Wheels were done on paper and not with a computer. Once I had the opportunity to re-write the Futures Wheel neatly, I scanned it and e-mailed it to the person interviewed in order to make sure that I had clearly understood what this person had meant and that there were no errors (see appendix n°3).

If modifications needed to be done, the interviewee re-explained the misunderstood “bubble” in order to have the correct version. Below is a table that summarizes the number of Futures Wheel that needed to be modified.

**Table n°1: Summary of Futures Wheels to be modified**

<b>Name of person interviewed</b>	<b>Modifications</b>	<b>Number of "bubbles" to modify</b>
Julien Sportisse	NO	N.A
Luc Berger	YES	1
Vanessa Hanifa	NO	N.A
Frank K. & Katrin R.	NO	N.A
Pascale Boyer-Barresi	NO	N.A
Urs Schneider	NO	N.A
Julia Dmitrieva	NO	N.A
Dr. Herter Clavel	NO	N.A
Rosamund Snow	NO	N.A
David Gilbert	NO	N.A

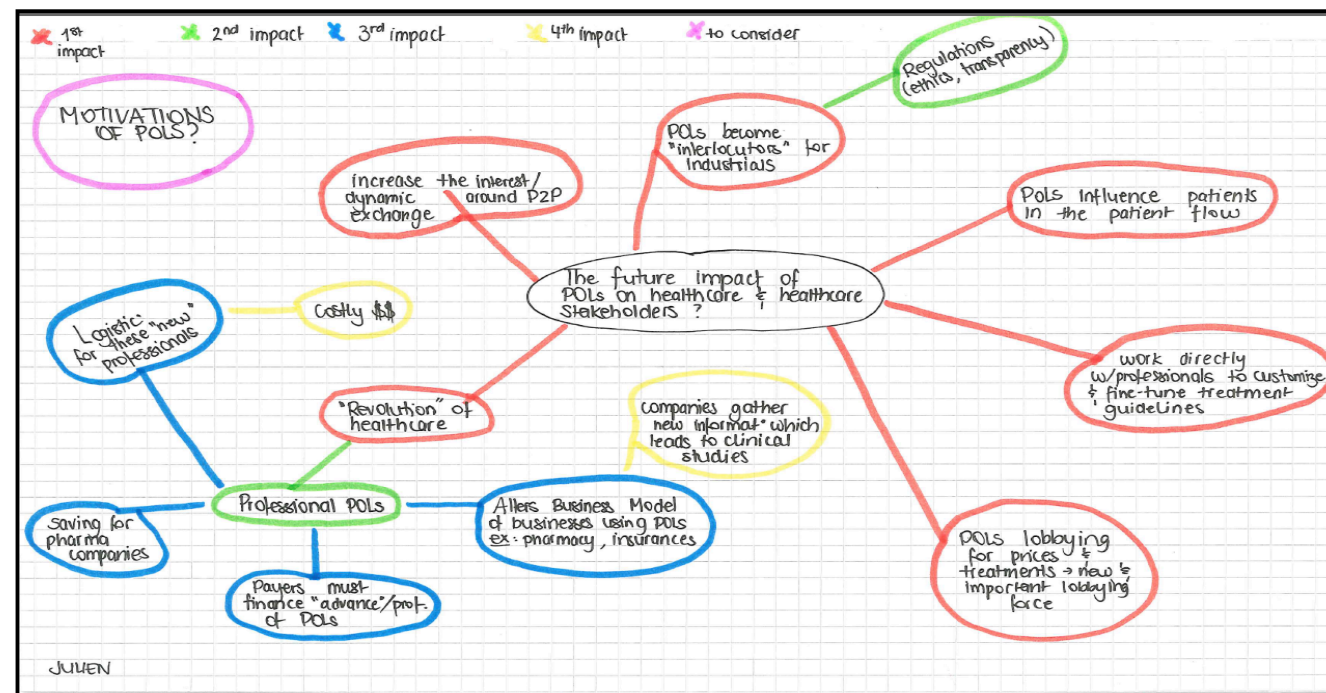
*Source: Meryl Dix (2015)*

### 3. Results

#### 3.1. Example of Futures Wheel

Below is an example of a Futures Wheel that emerged from my interview with Julien Sportisse.

**Figure n°4: Futures Wheel – Julien Sportisse**



Source: Julien Sportisse & Meryl Dix (2015)

## 3.2. Interviewees

### 3.2.1. Number of individuals contacted

Below are two tables that summarize the number of people I contacted to be interviewed and their responses. I categorized the various individuals into two different types of interviewees:

- Professionals (for short biography see appendix n°1)
- Patient Opinion Leaders (for short biography see appendix n°1)

**Table n°2: Summary of people contacted & interviewed (professionals) & referrals**

Professionals						
Name	Answer	Medium of contact	Interview	Reason for not interviewing	Referrals	Number of referrals
Julien Sportisse	YES	E-mail	YES	N.A	YES	1
Luc Berger	YES	E-mail	YES	N.A	NO	0
Yann Ferrisse	NO	E-mail	NO	No/little knowledge about subject	NO	0
Vanessa Hanifa	YES	E-mail	YES	N.A	YES	1
Maude Greutert	YES	E-mail	NO	No/little knowledge about subject	NO	0
Anna Fernandez	YES	E-mail	NO	Stopped answering e-mails	NO	0
Frank Kumli	YES	E-mail	YES	N.A	YES	1
Frédéric Thomas	NO	E-mail	NO	N.A	NO	0
Dafne Chirivino	YES	E-mail	NO	No/little knowledge about subject	NO	0
Pascale Boyer-Barresi	YES	E-mail	YES	N.A	YES	1
Urs Schneider	YES	E-mail	YES	N.A	YES	1
Charlotte Cottet	YES	E-mail	NO	No/little knowledge about subject	NO	0
Emilie Vinolo	YES	E-mail	NO	No/little knowledge about subject	NO	0
James Barlow	YES	E-mail	NO	No/little knowledge about subject	NO	0
Katrin Radl	YES	E-mail	YES	N.A	NO	0
Sonja Rothfuss	NO	E-mail	NO	N.A	NO	0
Dan Cote	NO	E-mail	NO	N.A	NO	0
Marco Lama	NO	E-mail	NO	N.A	NO	0
Jitka Kolarova	NO	E-mail	NO	N.A	NO	0
Aline Criton	NO	E-mail	NO	N.A	NO	0
Julia Dmitrieva	YES	E-mail	YES	N.A	YES	1
Grégory Katz	NO	E-mail	NO	N.A	NO	0
Gérard de Pouvoirville	YES	E-mail	NO	No time available for interview	NO	0
John Ko	YES	E-mail	NO	No time available for interview	NO	0
Samuel Constant	NO	E-mail	NO	N.A	NO	0
Dr. Herter Clavel	YES	Telephone	YES	N.A	NO	0
Rodolphe Renac	NO	E-mail	NO	N.A	NO	0
Céline Sportisse	YES	E-mail	NO	E-mailed for referrals only	YES	4
Xavier Pinardon	NO	E-mail	NO	N.A	NO	0

Source: Meryl Dix (2015)



**Table n°3: Summary of people contacted & interviewed (POLS) & referrals**

POLS						
Name	Answer	Medium of contact	Interview	Reason for not interviewing	Referrals	Number of referrals
Emilie Lecointe	NO	E-mail	NO	N.A	NO	0
E-patient Dave	YES	E-mail	NO	Stopped answering e-mails	NO	0
Andy Behrman	NO	E-mail	NO	N.A	NO	0
Patient Opinion website	NO	On website	NO	N.A	NO	0
Alexander Schachinger	NO	E-mail	NO	N.A	NO	0
Kym Martin	NO	E-mail	NO	N.A	NO	0
Tessa Richards	YES	E-mail	NO	Not well - ill	NO	0
Rosamund Snow	YES	E-mail	YES	N.A	NO	0
David Gilbert	YES	E-mail	YES	N.A	NO	0
Trow Richards	NO	E-mail	NO	N.A	NO	0
Ashay King	NO	E-mail	NO	N.A	NO	0
Dominique Forsch	NO	E-mail	NO	N.A	NO	0

Source: Meryl Dix (2015)

### 3.2.2. Number of individuals interviewed

The table below summarizes the statistics of the number of individuals interviewed, the number that answered and their relevant percentages.

**Table n°4: Interview statistics**

Number of individuals contacted	Number of individuals that answered	Number of individuals I interviewed	Percentage of individuals that responded	Percentage of individuals interviewed
41	22	10	54%	45%

Source: Meryl Dix (2015)

## 3.3. Cartography from Gephi software

### 3.3.1. Google spreadsheet

Once all of the interviews had been conducted and the Futures Wheel validated by the interviewees, I input the data of each Futures Wheel into a Google Spreadsheet so that Mr. Gauthier, Mr. Fonta and I all had access to it. The Google Spread sheet was separated into two major columns that each had three sub-columns as seen in figure n°5. The first major column was entitled *start bubble* and had the following sub-columns: title of bubble, tendency and commentary. The second major column was entitled *end bubble* and had the same sub-columns as the first major column.

**Figure n°5: Google Spreadsheet – Dr. Urs Schneider**

	A	B	C	D	E	F	G
	Start bubble			End bubble			
	Title of bubble	Tendency	Commentary	Title of bubble	Tendency	Commentary	
3	What are the future impacts of Patient Opinion Leaders on healthcare and healthcare stakeholders?			Provide patients with evidence based medicine	1	Provides an unbiased view of medicine	
4	Provide patients with evidence based medicine	1		Have the "best of the best" doctors	1		
5	Have the "best of the best" doctors	1		Saving money for patients & insurances	1	Example: no unnecessary surgery	
6	What are the future impacts of Patient Opinion Leaders on healthcare and healthcare stakeholders?			Have an unbiased view of their condition	0		
7	Have an unbiased view of their condition	0			0		
8	Changed business model for business using POLS	1		Creation of Internet based platform	1		
9	Internet based platform	1		General Practitioner can communicate on this platform	1		
10	What are the future impacts of Patient Opinion Leaders on healthcare and healthcare stakeholders?			Patients know best doctors by gathering information for POLs	1		
11	Patients know best doctors by gathering information for POLs	1		Creation of foundations/platforms of POLs who know best doctors	1		
12	Creation of foundations/platforms of POLs who know best doctors	1		New education models for General Practitioners	1		
13	Creation of foundations/platforms of POLs who know best doctors	1		General Practitioners function's changes with access to platform	1		
14	Creation of foundations/platforms of POLs who know best doctors	1		General Practitioners can check his/her knowledge	1		
15	General Practitioners can check his/her knowledge	1		Patients save money	1		
16	Creation of foundations/platforms of POLs who know best doctors	1		Conditions are explained to patients	1		

Source: Thomas Gauthier, Dr. Urs Schneider & Meryl Dix (2015)

The Google spreadsheet was filled out by starting off with the first “*start bubble*”, which was always the question of my project: what are the possible future impacts of Patient Opinion Leaders on healthcare and healthcare stakeholders?

Then always reading the Futures Wheel from the interview in a clockwise motion, I proceeded to fill in the Google spreadsheet. As an example, consider the Futures Wheel that was created when interviewing Julien Sportisse (figure n°4). The first “start bubble” was the question of my project and the “*end bubble*” attached to it was “*POLS become spokespeople for industrials*”. As it can be seen in the figure n°6, this is what has been filled in on line 3.

**Figure n°6: Google Spreadsheet – Julien Sportisse**

	A	B	C	D	E	F	G
1	<b>Start bubble</b>			<b>End bubble</b>			
2	Title of bubble	Tendency	Commentary	Title of bubble	Tendency	Commentary	
3	What are the future impacts of Patient Opinion Leaders on healthcare and healthcare stakeholders?			POLS become spokespeople for industrials	1		
4	POLS become spokespeople for industrials	0		Guidelines and regulations need to be put in place	1		
5	What are the future impacts of Patient Opinion Leaders on healthcare and healthcare stakeholders?			POLS influence patients in the patient flow	1	Patient flow: presentation - diagnosis - treatment - decision - strategy	
6	What are the future impacts of Patient Opinion Leaders on healthcare and healthcare stakeholders?			POLS work directly with professionals to customize and fine tune their treatment guidelines	1	What should be done?	
7	What are the future impacts of Patient Opinion Leaders on healthcare and healthcare stakeholders?			Lobbying done by patients	1		
8	What are the future impacts of Patient Opinion Leaders on healthcare and healthcare stakeholders?			"Revolution of healthcare"	1	Patients are coached. Pharmaceutical companies can save money.	
9	"Revolution of healthcare"	1		Emergence of professional POLS	1		
10	Emergence of professional POLS	1			0	Example: hospitals, pharmaceutical companies	
11	Changed business model for business using POLS	1		POLS can influence research done by pharmaceutical companies	1		
12	Emergence of professional POLS	1		Payers must finance the emergence of professional POLS	0		

Source: Thomas Gauthier, Julien Sportisse & Meryl Dix (2015)

Then, I continued to proceed in the same manner until the whole Futures Wheel was input into the Google spreadsheet and done for every person interviewed.

### 3.3.2. Tendencies

Subsequently, the next step was to fill in the tendency column for each Futures Wheel. The first “*start bubble*” that was the question of my project (“what are the possible future impacts of Patient Opinion Leaders on healthcare and healthcare stakeholders?”) has no tendency as it is the primary question. For each of the other bubbles, tendency needs to be clarified in order to come up with the final cartography (see appendix n°7).

The tendency for each “bubble” can either be neutral (written as 0), positive (written as 1) or negative (written as -1).

A “bubble” has a neutral tendency when it has no impact but is not to be confused with having no tendency (only the bubble “what are the future possible impacts of POLS on healthcare and healthcare stakeholders?” can have no tendency). It has a positive tendency when there is more of the aspect in question and a negative tendency when there is less of the aspect in question.

As an example, consider the following “bubbles” and their tendency:

### Example of positive tendency:

**Figure n°7: Google Spreadsheet – Dr. Urs Schneider**

Start bubble			End bubble		
Title of bubble	Tendency	Commentary	Title of bubble	Tendency	Commentary
Conditions are better explained to patients	1		Patients trust their doctors	1	
Patients trust their doctors	1		Patients save money	1	
Conditions are better explained to patients	1		Drugs are sold	-1	

Source: Thomas Gauthier, Dr. Urs Schneider & Meryl Dix (2015)

One of the aspects discussed during my interview with Dr. Urs Schneider was the impact of “*conditions are better explained to patients*”. As shown in figure n°7, the tendency of “*conditions are better explained to patients*” is positive as more conditions are better explained to patients. The impact of “*conditions are better explained to patients*” is that “*patients trust their doctors*”. This has a positive tendency, as patients will trust their doctors more.

### Example of negative tendency:

**Figure n°8: Google Spreadsheet – Dr. Urs Schneider**

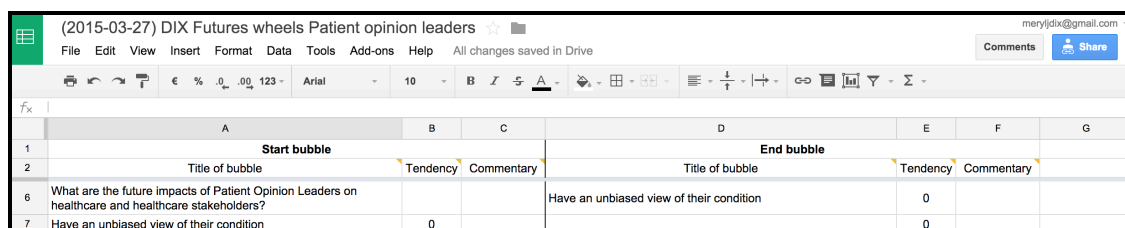
Start bubble			End bubble		
Title of bubble	Tendency	Commentary	Title of bubble	Tendency	Commentary
Conditions are better explained to patients	1		Drugs are sold	-1	
Drugs are sold	-1		Patients save money	1	
Conditions are better explained to patients	1			-1	

Source: Thomas Gauthier, Dr. Urs Schneider & Meryl Dix (2015)

In this example, because “*conditions are better explained to patients*”, less “*drugs are sold*” as patients will only purchase what they really need. As less “*drugs are sold*” the tendency is negative.

## Example of neutral tendency:

**Figure n°9: Google Spreadsheet – Dr. Urs Schneider**



	A	B	C	D	E	F	G
1	Start bubble			End bubble			
2	Title of bubble	Tendency	Commentary	Title of bubble	Tendency	Commentary	
6	What are the future impacts of Patient Opinion Leaders on healthcare and healthcare stakeholders?			Have an unbiased view of their condition	0		
7	Have an unbiased view of their condition	0			0		

Source: Thomas Gauthier, Dr. Urs Schneider & Meryl Dix (2015)

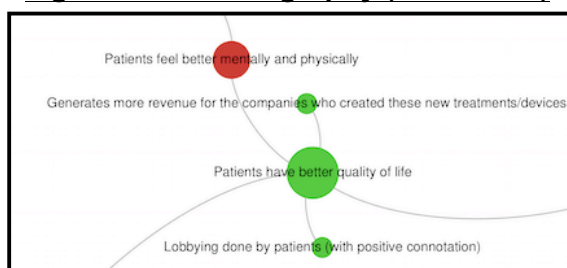
In this example, an impact of the main question is that patients will “have an unbiased view of their condition”. This has a neutral tendency (no impact) and is therefore expressed with a 0.

### 3.3.3. Explanation of the cartography

Once all of the “bubbles” for all of the interviews were input into the Google spreadsheet, Mr. Fonta was able to insert the data into the Gephi software in order to obtain the cartography (see appendix n°7). In order to read this cartography, three important tips need to be understood:

- **Size of knots (circles):** the more prominent and repeated a term was in the Google spreadsheet, the bigger the size of the knot. For example, “patients have better quality of life” was mentioned 5 times throughout the interviews and its size is considerably larger than “lobbying done by patients (with positive connotation)” which was only mentioned twice.

**Figure n°10: Cartography (zoomed in)**

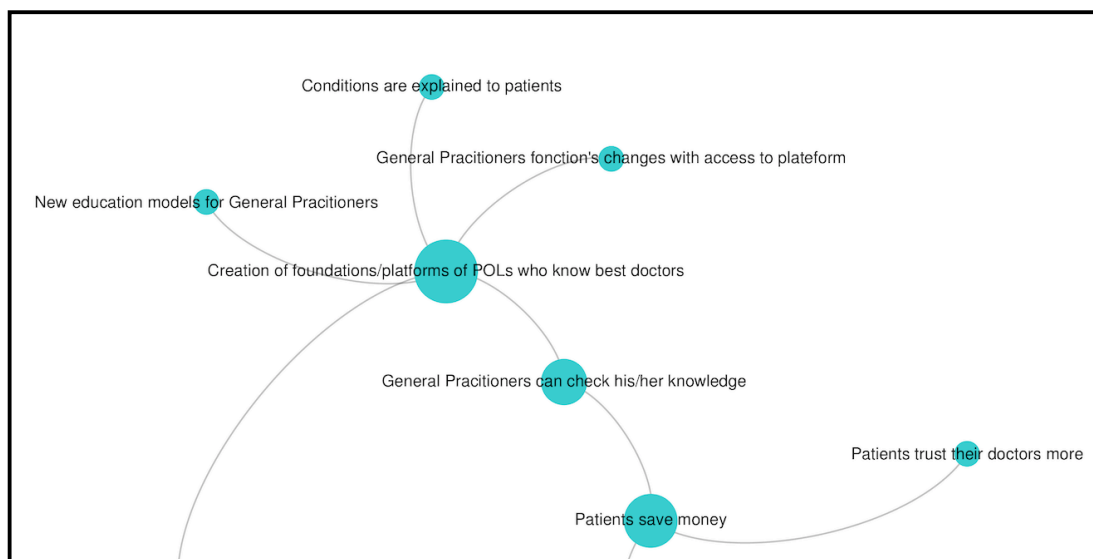


Source: Pierre-Alexandre Fonta (2015)

- **Color of knots:** the Gephi software automatically groups “families” that were often repeated as consequences of each other and that were often recurring together. The software then assigns a random color to the “family” of knots.
- **Spokes:** Knots are linked together by spokes. They are to be read in a clockwise manner and show a cause and effect relationship. For example, the knot “creation of foundation/platforms of POLS who know best doctors” (see figure n°11) has four impacts:
  1. Conditions are explained to patients
  2. General Practitioners function's changes with access to platform
  3. General Practitioners can check his/her knowledge
  4. New education models for General Practitioners

As another example, “General Practitioners can check his/her knowledge” has “Patients save money” as an impact. Whereas, “Patients trust their doctors more” has as an impact “Patients save money”.

**Figure n°11: Cartography (zoomed in)**



*Source: Pierre-Alexandre Fonta (2015)*

### 3.4. Scenarios

After the elaboration of the cartography there was one final step, which consisted in reaching out to the ten interviewees and asking three of them to come up with a feasible scenario for the future of Patient Opinion Leaders based on the cartography. I first sent out an email to all of the individuals interviewed (see appendix n°4). However, not having a response in the three days following this email, I decided to reach out to three of the interviewees, which I had had the best contact with. I discussed the possible future scenarios with the first three interviewees who responded to my e-mail.

#### 3.4.1. Scenario by Dr. Urs Schneider<sup>5</sup>

Nowadays, patients often feel neglected by their physicians when they have a chronic illness. They frequently have to visit many doctors before finding one that is thoroughly knowledgeable with their disease and well aware of the course of action(s) to take. This process is difficult for the patient but also for insurance companies (as they have to continuously reimburse doctor's appointments that aren't always necessary) and for physicians (as they often end up referring the patient to a colleague that is more educated on the subject).

In this sense, POLS could work hand in hand with a neutral agent such as a NGOs or an interest group (such as the United Cancer Research Society) in order to create a platform that helps patients find the "best of the best" doctors for their particular condition. This platform would help patients feel empowered, be created with objectivity and would "reward" the doctors that work the hardest.

The statistics would be collected by the state and would have categories such as: Dr. X was consulted XX times for a second opinion, Dr. X had XX patients come from abroad for an opinion or surgery, Dr. X has had XX successful surgeries.

POLS could be used for advertising purposes such as making videos explaining why Dr. X is an excellent doctor and what are the pros and cons of a certain treatment.

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<sup>5</sup> Interview with Dr. Urs Schneider, CMO & Medical Director DACH, Zurich, 18th of May 2015.

The result of this platform would be that patients have a better quality of life, as they would have saved time and money in finding the doctor that corresponds best to their needs. Insurance companies would have less appointments and treatments to reimburse, as the doctor chosen is the most experienced in this disease. Lastly, doctors would have an incentive to do their best work in order to come up on the platform and have more patients.

### 3.4.2. Scenario by David Gilbert<sup>6</sup>

As of right now, online platforms are already being used but are not very known to the general public. These platforms are slowly starting to feature reviews discussing the pros and cons of various drugs and treatments and potential side effects.

In addition to the creation of online platforms, a very plausible scenario is that pharmaceutical companies will start working hand-in-hand with Patient Opinion Leaders to help with logistics. The term logistics can be interpreted in different manners. However, in this case it corresponds to the creation of different apps (that inform the patient on treatments and/or physicians), devices and different technologies. Of course, the pharmaceutical companies will not be working alone, but rather collaborating with tech companies and private individuals or companies for investments. The POLS would help by giving their input and their “neutral” and patient centric point of view.

Much of the future of healthcare depends on better explaining conditions to patients in order for them to make more informed choices about their conditions. When patients are more informed about their condition, they are able to make decisions accordingly and in collaboration with their doctor rather than having to take their doctors’ opinion and not understanding exactly what this implies or the possible consequences. Having more informed patients will lead to a change in the selling of drugs, as patients will either take more drugs or less depending on their knowledge.

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<sup>6</sup> Interview with Mr. David Gilbert, Patient Director, Sussex MSK Partnership, Sussex, 19th of May 2015.



### 3.4.3. Scenario by Vanessa Hanifa<sup>7</sup>

The most feasible scenario is a mixture of two elements that can be seen on the cartography and that are very closely linked. It regroups the creation of foundation/platforms of POLS who know the best doctors and the fact that this data will be available for patients, physicians and pharmaceutical companies to use.

Community website and blogs already exist but do not put forward the “best doctors”. POLS could help with creating this platform that could have an influence on other patients. Doctors and pharmaceutical companies could also have access to this platform and would be able to communicate with patients on it.

Pharmaceutical companies could be involved in the creation of the platform and could help in terms of logistics. The result of this platform would be that patients are more informed and therefore understand their disease(s) better. They would be able to make more informed decisions when it comes to what treatments to adopt. The platform would also allow physicians and pharmaceutical companies to have a patient's view and could help them in becoming more patient centric.

This fore coming trend is something that needs to be acknowledged by pharmaceutical companies and physicians in order for them to make the necessary changes and adapt to this rising trend.

### 3.4.4. Scenario by Meryl Jehan Dix

As a millennial, my first reflex is to check the Internet before making any decision concerning a product that I am looking to purchase and I strongly believe that I would do the same for any treatment or drug.

Additionally, during the course of my studies at the HEG, I have learned how powerful a tool word-of-mouth (WOM) really is. In past, I bought products simply because a friend, colleague or family member has recommended it and healthcare is not an exception.

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<sup>7</sup> Interview with Mrs Vanessa Hanifa, Consultant, Alcimed - Suisse, Lausanne, 27th of May 2015.

As an example, I recall an event that occurred a few months ago when I burned myself and a colleague recommended a certain cream that I hadn't yet heard of. I have been buying a different over-the-counter cream for the past 15 years for small superficial cuts and burns. However, my colleague convinced me to switch to her brand as she was very confident would help me heal faster. I ended up buying the new cream, which I had only heard of once simply because of my colleague's recommendation.

POLS use both the Internet and WOM to communicate their opinions about drugs, treatments, physicians, hospitals, pharmaceutical companies etc. In my opinion, the most probable scenario for POLS in the near future would be that they will change the dynamics between patients and doctors. After having interviewed Dr. Herter Clavel, I had confirmation of what I thought was already true. More and more patients come to her office, with printed recommendations from the Internet, about the condition they think they might have or what treatment they believe is best. Furthermore, I believe that patients who aren't POLS are already impacting the healthcare system without knowing it via WOM and the Internet. I also believe that POLS' impact (who have a bigger consequence than the lambda patient as they have followers on social media and blogs) will become more and more widespread.

This primary impact (the changing dynamics between the patient and doctor) will then engender a secondary direct consequence involving pharmaceutical companies. Pharmaceutical companies will start hiring POLS once they see the impact that they have on other patients. It is difficult to say what will be the exact job description of POLS. They might be used to advertise certain drugs/treatments by stating that it has worked in the past for them. They might take over the role that Key Opinion Leaders (KOLS)<sup>8</sup> currently have. Or it might be in a different and new manner. Whatever the role POLS may take on in the future, I believe that their impact and spread will become more and more significant in the years to come.

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<sup>8</sup> « Key Opinion Leaders are physicians who influence their peers' medical practice, including but not limited to prescribing behavior. Pharmaceutical companies generally engage key opinion leaders early in the drug development process to provide advocacy activity and key marketing feedback.” Source: Anonymous. 2015. Key Opinion Leaders. *The Pharma Marketing Glossary*. [ONLINE] [Accessed 23 May 2015]. Available at: <http://www.glossary.pharma-mkting.com/keyopinionleader.htm>

## 4. Discussion

### 4.1. Interpretation

#### 4.1.1. Patient Opinion Leaders: a cause close to their heart

An important factor to consider when analyzing the data given by POLS is the fact that this subject is very personal to them. By this I mean that they are speaking from experience as they have suffered from a disease that has governed or still governs their lives. It is because of this fact, that their answers may be biased and mixed with a lot of emotion. Both of the POLS I interviewed (and a few more I spoke to who did not accept to be interviewed) felt as though their government and their healthcare system did not take charge in their case/disease. It is due to this sentiment of neglect that I believe that their answers may be prejudiced. Both POLS interviewed also insisted on the fact that the healthcare system in which they were part of was not patient centric. However, when discussing this aspect with the professionals, they had the opposite view (this was specifically true during my interview with Dr. C. Herter-Clavel). These professionals, all stakeholders in healthcare, believe that medicine is becoming patient centric and has been doing so for years.

#### 4.1.2. The real motivation of POLS

As can be seen in appendix n°6, some of the professionals expressed an interest in knowing the real motivations of Patient Opinion Leaders. Are they expressing themselves on the Internet to help others? Are they doing so to have more followers? Are they looking to be “famous”? As this was not a direct consequence of the question (first bubble of the Futures Wheel), I chose to incorporate the bubble into the Futures Wheel without it being “attached” to the rest of the wheel.

#### 4.1.3. Examples of interpretation of “bubbles” in Futures Wheel

Another important aspect to discuss is the interpretation of each “bubble”. Indeed, not every individual used the same wording to describe a certain impact. However, I found that most of the time, the interviewees were in fact discussing the same aspect of the question. To this effect, I had to modify the wording of the bubbles to ensure that even if wording was different but the meaning the same, the bubbles could be input in the Gephi software to have to same significance.

Because of this, there is room for error in interpretation and re-wording. As an example, consider the Futures Wheels that was drafted after having interviewed Julia Dmitrieva (see appendix n°6) who was the 7<sup>th</sup> individual to be interviewed.

While discussing the future impacts of Patient Opinion Leaders, the aspect of clinical research came up. Indeed, Mrs. Dmitrieva stressed the fact that in the future, POLS may be able to influence clinical research done by pharmaceutical companies. Her exact words were: “the medical community starts doing more research as POLS start to have more influence”. This aspect had already been mentioned by another interviewee but had been phrased: “POLS can influence research done by pharmaceutical companies”. Both of these statements had the same meaning but were phrased in two completely different manners. The Gephi software is unable to detect that these two sentences have the same connotation, as the exact same words aren’t used. It was therefore up to me to change the wording to ensure that the software could draft the cartography in the best way.

#### 4.1.4. Mental vs. physical conditions

While discussing conditions with POLS the difference between mental health and physical chronic conditions emerged. The main dissimilarity to come up was the fact that when dealing with mental health, patients don’t usually have a say in the treatment that is administered to them, what side effects they will have and their overall physical state. So the main concern for a patient that has suffered from a mental illness is the choice of treatments whereas the concern for a patient suffering from a physical condition is the physician and the treatment administered. In this sense, the cartography might be truer for physical conditions rather than for mental ones as all of the interviewees (with the exception of one) discussed physical conditions when interviewed.

#### 4.1.5. Cartography from Gephi software

The cartography that resulted from the interviews is extremely complex. Removing a knot can have an enormous impact not only on the knots closely linked to it by spokes but also on the entire cartography.

Reading the cartography is extremely subjective, as not every individual will interpret the wording of each knot in the same way. Moreover, not every individual will infer the impacts of each knot in the same manner.

However, this is also one of the important strengths of the cartography because as different people read it, more possible scenarios will emerge, which will give a better glimpse of what the future may look like.

#### 4.2. Limitations of my project

As stated in the introduction to this paper, the Futures Wheel method has several advantages and limitations. This is especially true when it comes to discussing the fact that the Futures Wheels are the product of the knowledge and understanding of each individual interviewed. In this specific case, the interviewees were chosen due to their ties and knowledge to the subject of the healthcare industry. In this sense and as for every Futures Wheel, some impacts could have been forgotten.

Also, as discussed in my introduction, there are two types of POLS. During my interviews, I spoke to each “kind” of POLS. Because each kind of POLS has a different aim (one to help others and the other to be active on the advocacy front), they both had a different vision of probable impacts. The fact that I interviewed both is not an issue. However, the fact that two different types of POLS existed is something that I only came across after having conducted more than half of the interviews. If I had come across this in the early stages of my project, I would have been able to conduct the interview while separating these two aspects, which might have led to a different cartography.

When discussing healthcare with the different interviewees, I realized that healthcare varies from one country to the next. In this sense, I believe that not all impacts/bubbles concerning healthcare are valid for each country. To give a concrete example, consider the following: one of the POLS interviewed told me about her personal experience with her disease and how the treatment she needed was not refunded by her insurance but would have been were she resident of her neighboring country. This led me to conclude that the project is not specific to any country and may have impacts that are not relevant to all countries.

When all of the interviews were conducted and the Futures Wheels drafted and controlled, I proceeded to ask the interviewees to come up with scenarios for the future based on the cartography. I e-mailed all of the individuals that participated in the interviews.

However, because I was constrained by time, I chose to reach out in a more aggressive manner to the interviewees that I either knew personally or that I had had a good contact with. This without doubt created a bias when it comes to the proposed scenarios as not every interviewee was given an equal chance in being interviewed in order to discuss a futures scenario.

To summarize, the major limitations of my project include the disadvantages of using the Futures Wheel method, the interpretation due to inputting the data into the Gephi software to ensure that a bubble with different wording but with the same meaning were regrouped, the aspect of healthcare that varies from one country to the next, that the cartography is based mostly on physical conditions rather than mental ones and the bias created as I was constrained by time.

#### 4.3. Difficulties met during project

During the time I worked on this project, I encountered many different types of difficulties. Some were more of an inconvenience, while others pushed me to make decisions that I might not have taken had I not been inconvenienced.

The main issue I came across was the fact that I was, during half of my project, dependent on other people's input and schedules. Researching the problem of my project was done through interviews of individuals that are all active professionally. This meant that I was constantly trying to find individuals to interview that were able to allocate time to my project.

The second issue that played an enormous part was timing. Collecting data through interviews, inputting that data into the Google document, inputting data into the Gephi software, interviewing individuals for a futures scenario and writing the actual paper are all tasks that take an enormous amount of time. If I had had more time at my disposal, I might have been able to make my decisions differently. For example and as stated in the limitations part of my paper, when I did not receive any positive answers for the elaboration of the futures scenarios from the 10 individuals I had previously spoken to, I reached out to three of the individuals I had had the best contact with and whom I thought would be more willing to speak to me. In that sense, I created a bias and did not give the other 8 people the same opportunity. Furthermore, when I first started contacting POLS for an interview, I came across a number of individuals who were starting to become very well known as POLS.

Again, because of people's schedules and to my great regret, I was not able to interview certain individuals, as they were only available starting June 2015, which was after the deadline to turn in my project. The results of my cartography would have been different would I have been able to do so.

I believe that researching this problem by interviewing individuals that are closely linked to the medical industry was an excellent way to pursue this project. Crowdsourcing<sup>9</sup> has many different methodologies such as the Futures Wheel for gathering people's opinions and as stated in this paper, it offers many advantages. However, having experienced the differences between conducting a face-to-face interview and telephone interviews, I would recommend interviewing as many individuals face-to-face as possible. Doing so offers many advantages. The Futures Wheel can be visualized by the interviewee, which will allow him/her to organize his/her thoughts in a more efficient manner. He/she will understand the process better, which will then allow him/her to better understand the mechanism of the wheel. Moreover interviewing a person face-to-face provides the opportunity to read a person's body language and facial expressions. This is important when discussing subjects that can be very personal and difficult. This is most certainly true when interviewing POLS and the predisposition they might have when discussing their disease(s) and past experiences.

Crowdsourcing is an intricate process that has many steps and requires an enormous amount of organization. The three individuals I spoke to for the elaboration of futures scenarios all exhibited similar behavior. When elaborating a future scenario two of the three interviewees discussed the same points they had covered during the first interview (when the Futures Wheel was created). This was not done purposefully. Should I have to conduct a similar research in the future, I would present a cartography without the interviewee's answers to make sure that they do not neglect the rest of the data collected. The aim of the cartography was to have an aggregation of the data collected from the 10 interviewees and expose the interviewees to a helicopter view of the situation. However even though unintentionally, this tool was not used to its full potential.

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<sup>9</sup> The process of gathering information from a large crowd (a conjunction of the word crowd and sourcing).

Out of all of the inconveniences I mentioned above, I believe that none could have been avoided, as I didn't have the knowledge I have now. Being dependent of people's input is an inconvenience but has in no way impacted the quality or results of this project.

Nevertheless, I believe that the problematic of timing did affect the results of the cartography. Furthermore, the fact that the cartography was not used in the intended matter also affected the elaboration of the scenarios.

#### 4.4. Who could profit from this project

The subject of POLS is still emerging and little research has been done on this subject. The research that has been conducted and that is available is anecdotal and often done from a very personal point of view. This project is pertinent as it offers a first look at what is the future of Patient Opinion Leaders and would serve any person who is interested in knowing more about the subject and any stakeholders.

Below I chose three of the stakeholders that came up the most during my interviews and developed why this project could be important and helpful to them.

Patient Opinion Leaders could impact **pharmaceutical companies** by lobbying the government for the re-imbursement of certain drugs and by influencing what clinical research should be done. In the near future, pharmaceutical companies might also decide to hire POLS as speakers or advertisers in order to guide certain patients (by discussing their personal story) on what treatments they might choose to use. In any event, pharmaceutical companies could have a better outlook on how the growing and expansion of POLS may affect their business model with this project.

**Physicians** are one of the stakeholders that are directly in contact with the patient. The project could inform them on what may be coming as patients increasingly research their conditions on the Internet and the power of WOM before going to see their doctor. Moreover as POLS are becoming more prominent, they are changing the way the doctor is viewed by patients and this is something physicians must be aware of in order to adapt to this changing dynamic.

As said above, because POLS are becoming more wide spread, the next step could involve their hiring by pharmaceutical companies in order to promote a certain drug or treatment.



This, of course, will then require **regulating agents** to come up with guidelines or rules that must be followed by pharmaceutical companies as this could be seen as an ethical gray zone. Regulating agents should be aware of this in order to prepare in advance for this possibility.

## 5. Conclusion

The healthcare industry is constantly evolving because of breakthroughs in treatments and drugs directly linked to the industry and also because of the changing and evolving times that we currently live in.

The notion of Patient Opinion Leaders is still a very new one. Research on the subject is scarce and even people with a close link to the healthcare industry aren't always aware that the acronym exists or of its exact significance.

The deeper and more involved I became in the project, the more I became convinced that POLS would become an important part of the healthcare industry. This will take time and most certainty will not happen exactly as it has been outlined in the final cartography that came from this project. I also believe that these patients can bring their knowledge to both other patients and healthcare stakeholders simply because they have a different view of the problem and that no one will ever be as concerned by a disease, treatment or drug then the person living with it.

The results that have emerged from this research paper are multifaceted, intricate and can lead to subjective interpretation. As it has been said above, the methodology of the Futures Wheel is only as good as the people who complete the wheel, which is why this project probably only covers a small part of what can be said on the subject.

Moreover, this project has lead me to ask myself more questions than I had when I started out. The methodology has some limitations as discussed in this paper. However, finding a method to gather collective intelligence from a population is quite challenging. However, once it is done, it can be a very powerful tool. It broadens people's thinking, helps to have a helicopter view and most importantly leads to more questions that might not have been thought of.

It is now imperative to understand that Patient Opinion Leaders are a prominent group of individuals and that many healthcare stakeholders will be affected by their "rise". Consequently, impacted stakeholders should take this into consideration in order to make the necessary changes to prepare for what will occur soon enough.

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#### **Papers:**

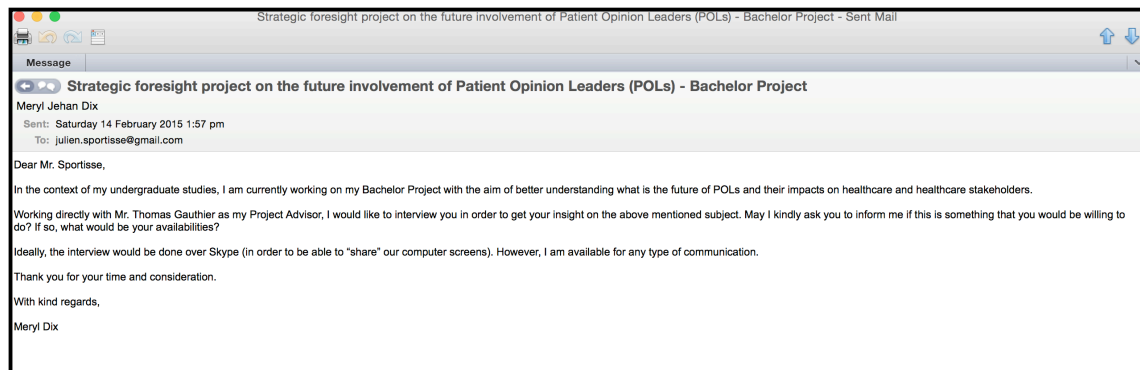
- Glenn, Jerome C., 1994, AC/UNU Millennium Project, *The Futures Wheel*,  
Futures Research Methodology

## Appendix n°1: Short biography of interviewees

Name	Company	Profession	Short bio
<b>Professionals</b>			
Julien Sportisse	ZS Associates	Consultant with specialization in pharmaceutical companies & biotech	Julien spent the last eleven years analyzing healthcare organizations, their business models and strategies to cope with information technology, changing consumer behavior and large-scale emerging trends.
Luc Berger	Alcimed	Business Unit Director for Healthcare	Luc is responsible for the development of key clients needing consultant help in the healthcare industry.
Vanessa Hanifa	Alcimed	Consultant	Within Alcimed, Vanessa has conducted more than 100 projects related to life sciences. Vanessa has been especially in charge of conducting projects aiming at evaluating the potential market of a new product / technology, in building the corresponding business plan and in elaborating the best market entry / reinforcement strategies. Vanessa is now in charge of the Food Business Unit in Switzerland.
Frank Kumli	Ernest and Young	Senior Manager - Global Life Sciences Center	Frank has over 15 years industry and consulting experience in projects focusing on commercial innovation. Frank currently specializes in Innovation in the field of healthcare delivery, with a special focus on innovative business models for Life Sciences companies. He develops 'Beyond the pill' strategies for Life Sciences players, exploring potential new business models for healthcare delivery with revenue streams
Pascale Boyer-Barresi	Debiopharm	Associate Director, Financial & Business Analysis, Communication, Business Development & Licensing	Pascale has 5-years of experience in the Pharmaceutical Sector in Financial & Business Analysis allowing the strengthening of several hard skills (data models & visualization, stress-testing, financing schemes, deal strategy). Implementation and customization of several methodologies (sales forecasts, project and company valuation).
Urs Schneider	Phillips	CMO & Medical Director DACH	Urs specialties include Clinical & Research interests are life & health insurance, congestive heart failure and emergency response and transport
Katrin Radl	Ernest and Young	Performance Improvement Consultant	N.A.
Julia Dmitrieva	Phillips	Senior Product Manager, Ultrasound, Growth Segments	Julia is a results oriented leader with proven success record in diagnostic imaging industry. She is a expert in strategic marketing, product management and healthcare operations. Specialties: global marketing; business strategy; market segmentation; product positioning; CSR; WHC; Radiology; quantification applications; general, vascular ultrasound and women's Imaging; PACS.
Dr. Herter Clavel	Own doctor's office	General Practicien	After studying at the Geneva Medical School and graduated in 1991, Dr. Clavel completed her internist training at the University Hospitals of Geneva and obtained her specialist in internal medicine in 1998.  She continued her training in geriatrics and validated in-depth training in geriatrics in 2002. Very interested in teaching, she joined the dynamic team of UEMPR in September 2009
<b>Patient Opinion Leaders</b>			
Rosamund Snow	Oxford University & BMJ	Researcher	Rosamund is currently working within the Department of Primary Care Health Sciences at Oxford University, evaluating and developing public involvement in medical education. During one day a week, she is contracted to the British Medical Journal as Patient Editor, working with the Journal's existing Editorial Board as part of an initiative to advance patient partnership throughout the BMJ Group.
David Gilbert	Sussex MSK Partnership	Patient Director	Patient Director, Sussex MSK Partnership and also Director of InHealth Associates (wWe support patients, service users, carers and citizens to work with professionals as equal partners for change). David is a former mental health service user with over 25 years experience in patient/user and public engagement at local, national and international level.

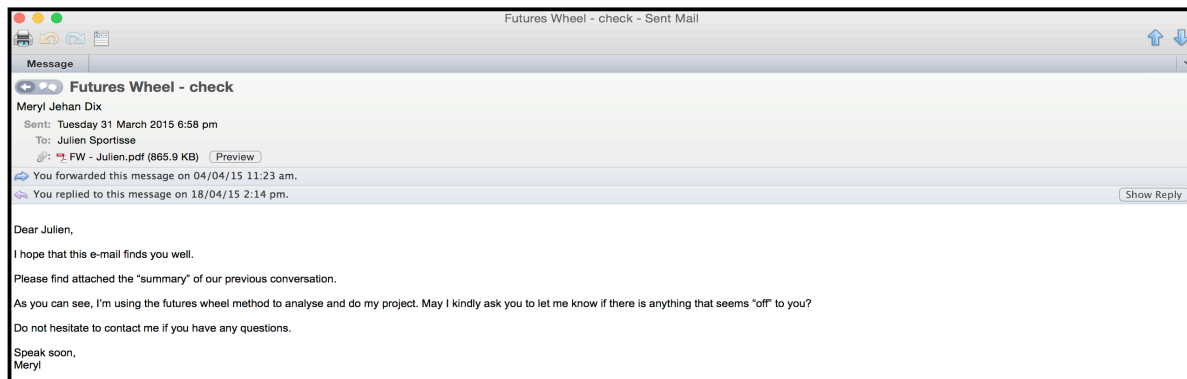
Source: Meryl Dix (2015)

## Appendix n°2: E-mail sent for first contact



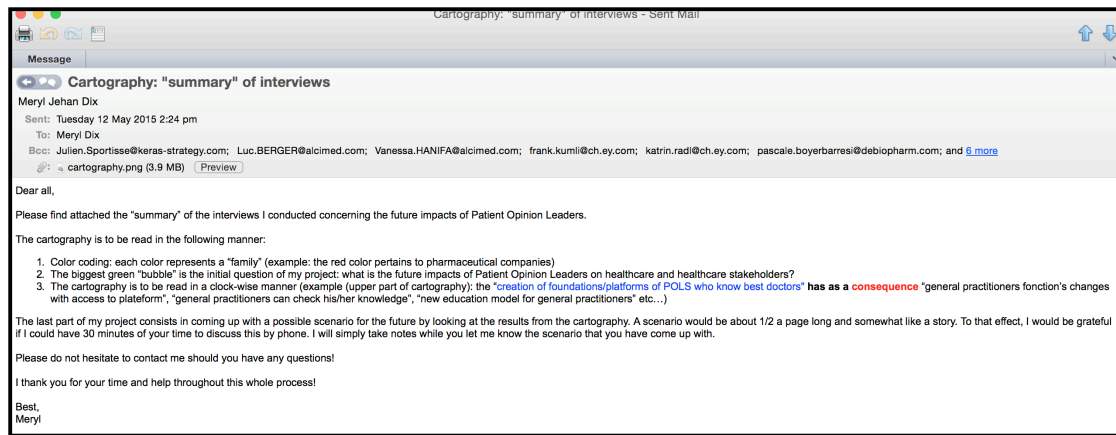
*Source: Meryl Dix (2015)*

## Appendix n°3: E-mail sent for confirmation of Futures Wheel



Source: Meryl Dix (2015)

## Appendix n°4: E-mail sent for scenario



Source: Meryl Dix (2015)



## Appendix n°5: Interview with Mrs. Pascale Boyer Barresi

Date: 26.3.2015

Interviewee name: Pascale Boyer Barresi

Start time: N.A.

End time: N.A.

Proposed interviewees: N.A.

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### **Short presentation of who you are; what is your tie to the Pharmaceutical Industry?**

*I graduated in Economics at the University of Fribourg in 1998 and worked in several banks as an equity analyst following and recommending investments in the pharmaceutical industry. I moved to the pharma industry in 2010 and I'm now responsible for sales forecasts and project valuation. I'm also well informed of industry trends as I'm responsible for data curation for the whole company with the publication of a weekly newsletter.*

### **Are POLs a valuable asset to Pharmaceutical Companies? Are they, in your opinion, worthwhile perusing?**

*POLs are a valuable asset to pharma companies because they are suffering from a diseases, they are looking for answers on the web and lastly they are the "final destination" of the treatments developed. They are very often well informed people having blogs about their disease and informing patients about new treatment alternatives and new ways to cure or care for the disease they are suffering from. By using them, pharma companies will have a direct insight and contact in the real patient's life and their real issues & worries. This will not be filtered away by healthcare providers focusing on medical points.*

### **What is the role of POLs today? How do they impact Pharmaceutical Companies now? Do PCs see POLs as a threat?**

*See the previous question for the role.*

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*Pharma companies need to take them into account and to include them in clinical development as the patient voice is more and more important for 2 reasons: 1. Because as healthcare systems are now under pressure, an increasing portion of the treatment cost is shifted to the patient (he/she will act like a consumer and will be willing to take drugs that bring him/her value and quality of life instead of just prolonging life). 2. Because of the information that is widely available on the internet and the patients are now well informed and would like to have their voice in their treatment choice.*

*POLs are not a threat but a huge opportunity to be closer to the patients and help them in coping with their disease.*

**To your knowledge, to what extent are Pharmaceutical Companies already working with POLs?**

*Some big companies like like Pfizer with this campaign launched in specific countries only (<https://www.youtube.com/watch?v=IOIX6Gc6WLo>) are showing there are committed to care for patients. Novartis is using them. Boehringer Ingelheim is also close to the patients. The real use of POLs is difficult to confirm as you have to be an employee. The use of POLs is not really communicated by big pharma.*

**Can you give me concrete examples of POLs working with Pharma Companies?**

*I don't have any name but check health blogs for multiple sclerosis and chronic diseases. Check also the website [patientslikeme.com](http://patientslikeme.com)*

**Do Pharma Companies track how their competitors use POLs?**

*I don't know.*

**How would you go about identifying POLs (which what means &tools)? What is your opinion on "POL internet sites" such as *patientslikeme*? Have you heard of Klout scoring and what do you think of this particular tool?**

*Patientslikeme is a good initiative, it is financed by pharma companies. It is a good way to gather patients and let them exchange on their diseases. It has the same*

*drawbacks as any other social media like Facebook or Twitter with fake profiles and high intensity profiles having their say all the time.*

*I know the Klout score but it does not always reflect correctly the online influence as some POLs are maybe not aware of its existence.*

**How would measure a certain POL's influence on other patients/potential patients? Do you think they have greater impact then KOLs and why?**

*I would check their blog and interact with them in order to have access to the blog stats or check them on alexa.*

*They will never have a greater impact than KOL as they are not in the same field. Both are important: KOL are here for scientific reasons as well as medical practice. POLs are here to share their experience but they won't have any say from a science standpoint.*

**Imagine a scenario where a Pharmaceutical Company wants to hire a POL, what are the probable impacts (impact of those impacts)? Do you believe this to be an ethical grey-zone? Moral and legal aspects to discuss.**

*The POL has to disclose its hiring by a pharma company as KOLs do. You will have to apply the same rules (ethics, regulation, disclosure) as it has been established with KOLs. There is a conflict of interest risk.*

**What's another scenario that comes to your mind?**

*None*

**Do you have strategies for countering positive POL impact for competitors?**

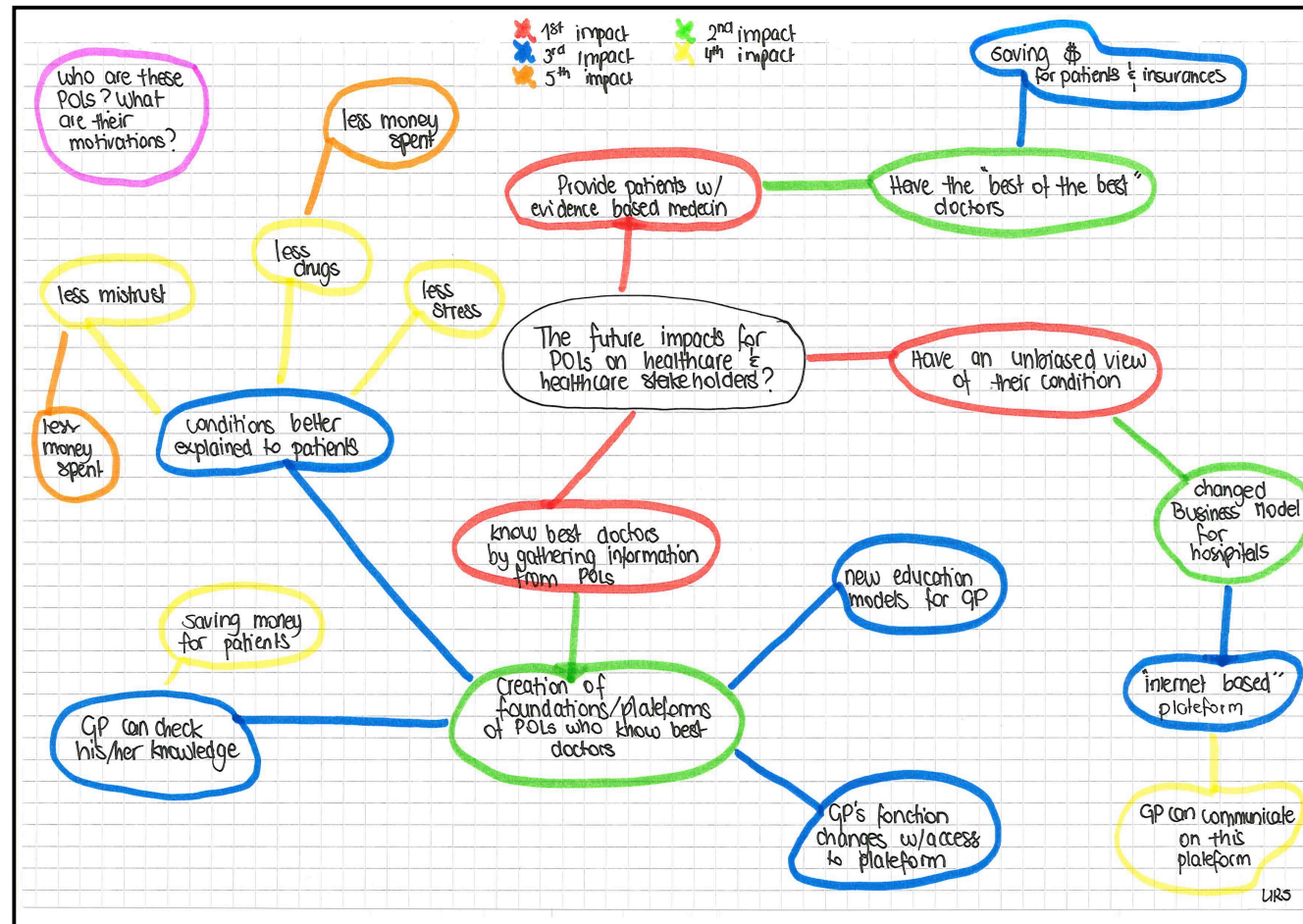
*No.*

**In your opinion, what role will POLs have in the future?**

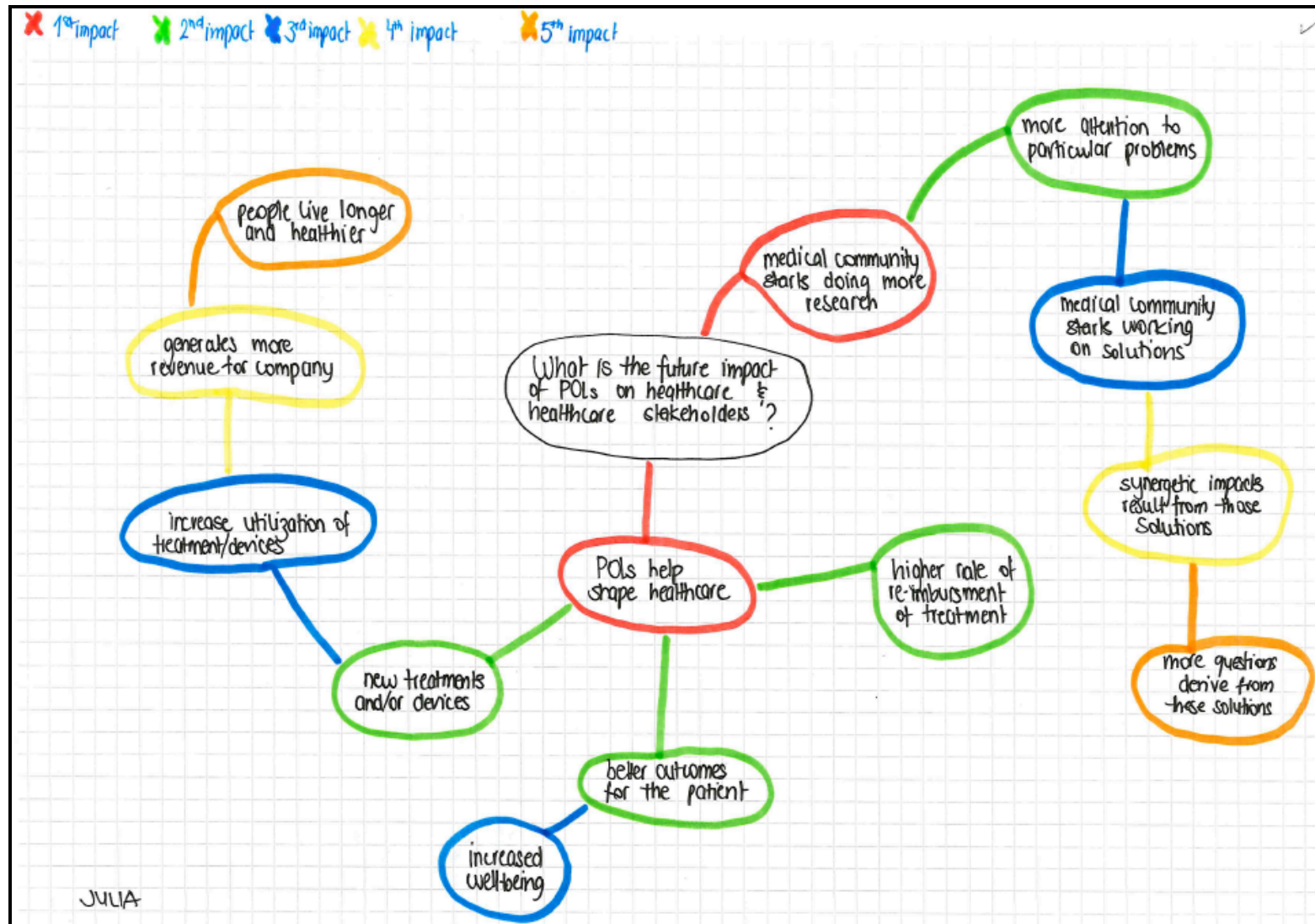
*See question 8 and previous*

*Source: Pascale Boyer Barresi & Meryl Dix (2015)*

## Appendix n°6: The Futures Wheels (more examples)



Source: Dr. Urs Schneider & Meryl Dix (2015)



Source: Julia Dmitrieva & Meryl Dix (2015)

"What are the possible future impacts of Patient Opinion Leaders on healthcare and healthcare stakeholders?"  
DIX,Meryl

